

**Hale, Nor na**

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**From:** Phil Sievers[[phil.sievers@state.mn.us](mailto:phil.sievers@state.mn.us)]  
**Sent:** Tuesday, December 11, 2001 3:11 PM  
**To:** [Lisa.Larson@house.leg.state.mn.us](mailto:Lisa.Larson@house.leg.state.mn.us)  
**Cc:** Rose Hermodson; Eric Kloos; Norena Hale; Tammy Pust; Lisa Backer; Michael Eastman; [Tom.Delaney@state.mn.us](mailto:Tom.Delaney@state.mn.us); [Genie.Potosky@state.mn.us](mailto:Genie.Potosky@state.mn.us)  
**Subject:** Autism: Legislative Request for Data

leg request for ASD  
cata doc

ASD Desc Study Leg  
Comm ppt

Executive  
summary doc

Lisa

I am forwarding this attached information in response to your request for data on Autism Spectrum Disorders (ASD) and school expenditures in Minnesota. I have gathered this data from several sources in our Department and our staff would be glad to answer any questions that might help clarify this data.

In addition to our responses to the specific data requests you made, I have also attached a Report and Executive Summary recently completed in collaboration with the U of MN. This ASD Descriptive Study was conducted as our request to more closely describe and analyze the increase in the Child Count for ASD reported by Minnesota school districts over the past 20 years.

I have also linked the report to an electronic resource; to provide more detailed definitions of the nature of the Special Education Services funded in question #3.

Please let Rose Hermodson [rose.hermodson@state.mn.us](mailto:rose.hermodson@state.mn.us) and me know if you need further information. I look forward to working together to provide accurate and current information on Autism Spectrum Disorders.

Phil Sievers, Ed.S.  
Consultant for Autism Spectrum Disorders  
Division of Special Education  
Minnesota Dept of Children, Families & Learning

email: [phil.sievers@state.mn.us](mailto:phil.sievers@state.mn.us)  
ph #: 612-638-1528

# **Autism Spectrum Disorders: A Descriptive Study**

## **Child Count Data from the Minnesota Department of Children, Families & Learning 1981-2001**

### **Executive Summary - November, 2001**

#### **Introduction**

This executive summary represents a synopsis of an analysis of data on Autism Spectrum Disorders (ASD) from the Minnesota Department of Children, Families and Learning (CFL). The goals of the analysis were to characterize the current number of individuals, being served by Minnesota schools the ASD disability category, quantify and describe ASD trends from 1981 - 2000, evaluate potential explanations for the trends, and estimate future trends. The data reported in this analysis includes the individuals, birth to 21 years of age, identified by multidisciplinary assessment *and* determined eligible for special education services under the disability category of ASD by all school districts. In collaboration with Phil Sievers, Specialist for ASD, Division of Special Education/CFL, the analysis was conducted, and a corresponding data presentation produced in PowerPoint, by James Surney and Melissa Fritz of the University of Minnesota, Department of Pediatrics, Division of Pediatric Epidemiology.

#### **Counts, Prevalence and Trends**

*Statewide Counts* The total number of children identified and reported to CFL with an ASD disability was relatively stable during the 1980's, ranging from 127 to 176 children per year. During the 1990's, however, a dramatic *and* steady increase was observed. In 1990, 189 children were included in the ASD special education category; by the end of 2000, that number had increased 15-fold to 2814.

*Regional Counts* At latest count, planning regions 11W (N=1099) and HE (N=752) of the Twin Cities together accounted for 1851 (about 65%) of the children in the State with an ASD disability. The increasing State trends during the 1990's were largely driven by regions 11W and HE. Region 5 was serving 289 children under *an* ASD disability in 2000 and region 7 had 270 such children. The corresponding number of children with an ASD disability in other State regions was: region 10 (N=182), region 9 (N=130), regions 1 and 2 combined (N=108), region 3 (N=107), regions 6 and 8 combined (89), and region 4 (N=71).

*Prevalence Rates* Because there is no statewide, population-based mechanism for reporting newly diagnosed ASD, true incidence rates cannot be calculated. Rather, the number of children identified by CFL with an existing ASD disability, relative to state childhood population estimates from the U.S. Bureau of the Census, was used to calculate ASD prevalence rates in Minnesota. From 1991 - 2000, a 9-fold increase in prevalence rates of ASD occurred in Minnesota. The current prevalence rate is estimated at 18.4 per

10,000 children ages 21 years or younger. The greatest increase, and the highest rates, were observed among children 6 to 11 years of age. In that age group, the prevalence rate increased 12-fold from 3 per 10,000 in 1991 to 38 per 10,000 in 2000.

### **Potential influences on ASD trends**

Increasing ASD trends can reflect several factors: 1) actual increases in incidence of ASD, 2) changes over time in identification or diagnostic criteria, 3) changes in administrative regulations or guidelines in reporting or service requirements, 4) changes in knowledge and awareness.

*Incidence* As mentioned previously, State data are not sufficient to evaluate true incidence rates. Changes in true incidence reflect changes in the balance of factors that cause disease. Several lines of evidence strongly support a genetic etiology for ASD, but it remains to be determined if specific environmental exposures can interact with genetic susceptibility to induce ASD occurrence.

*Identification/Diagnostic Criteria* No medical tests exist to diagnose ASD. Rather, ASD is identified or diagnosed based on behavioral criteria related to a spectrum of impairments in social interaction, speech and language deficits, and repetitive or rote behaviors. Accepted diagnostic criteria have undergone several modifications and revisions over the years. Some of these changes have widened the criteria for an ASD diagnosis, while others have narrowed the criteria. Although there is a general perception that changes in ASD diagnostic criteria, especially the clearer focus on *Asperger's Disorder*, has contributed to the higher prevalence rates, we were unable to directly assess that possibility.

*Categorization of an ASD Disability* Eligibility criteria in Minnesota rule does not require a medical diagnosis of ASD to place a child in the ASD disability category for services. Instead, it is the role of an IEP evaluation team to identify the primary disability category that most appropriately describes the nature of the child's disability and their needs and then provide services that are required to meet the educational needs of that child. Each child is assigned to only one category, even if he or she has more than one disability. Children with ASD may also be mentally retarded and always have some speech and language deficits. Therefore, some children with ASD may be classified in a disability category other than ASD. Increased awareness, decreased stigma, and increased ASD service benefits over time may have resulted in an increased likelihood that a child with ASD and other impairments will be included in the ASD disability category. The extent to which this phenomenon has contributed to the increase in prevalence could not be directly assessed in these data. Among children ages 6 to 11 years who received special educational services, however, the data do show that as the proportion in the ASD category increased, the proportion in several other categories decreased, most notably speech and language impairment.

*Administrative Changes* Several important federal and state changes occurred during the 1990's when ASD prevalence was increasing in Minnesota. From the mid 1970's until 1990, special education services were required under the auspices of the Education of the Handicapped Act and the Elementary and Secondary Education Act. ASD was not a disability category specifically recognized under these acts. Children with ASD, therefore, were most likely to be served under other special educational categories during that time. In 1990, all special educational programs were consolidated under the federal Individuals with Disabilities Education Act (IDEA). ASD became a reporting category under IDEA in 1991, which corresponds with the beginning of the dramatic rise in prevalence rates of ASD in Minnesota. In 1992, CFL began to implement a policy requiring *an* autism specialist be included *on* the IEP team of any child suspected of having ASD. Then, in 1994, IDEA became the sole source of educational funding for children with an ASD disability. Also during this year, the major diagnostic manual used to diagnose ASD (and other so called mental disorders) *released a revised version* which somewhat changed the criteria for ASD. In 1992, a CFL grant established the Minnesota Autism Network, a statewide technical assistance and promising practices training project. *An* additional 3 year grant in 1997 established ECSE/Autism Demonstration Projects focused on outreach and dissemination of information targeting intensive early intervention. The goal of these projects was to build capacity of staff, districts and regions to provide appropriate services for individuals with ASD. Each of these changes likely contributed to the ASD trends in Minnesota.

### Projections

Prevalence rates of ASD have risen substantially since 1990 and they show no current sign of leveling off. The current ASD rate in 7 year old children is 49 per 10,000. Roughly estimated, if ASD prevalence stabilizes at the current rate of the 7 year olds, 7000 children (birth to 21 yrs) will be included in the ASD disability category by the year 2005. If prevalence continues to rise at the current average increase of 21% per year, however, Minnesota could see over 10,000 children in the ASD disability category in 2005. Compared to the current Child Count of 2814, either projection suggests that Minnesota will experience a significant increase in the challenges to families, schools and communities to provide appropriate education and support.

Respectfully submitted in collaboration by:

J a m s & . Gurney, Ph.D.

Melissa Fritz

University of Minnesota

Phil Sievers, Ed.S.

Division of Special Education/CFL

November, 2001

## Autism Spectrum Disorders: A Descriptive Study

( had Count Data from the Minnesota Department of  
Children, Families & Learning 1981-2001

Presentation to Interagency Autism Coordinate  
December 4, 2001

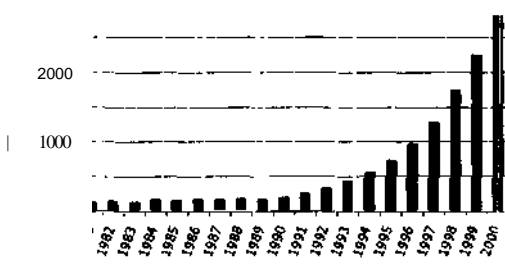
Developed in collaboration with  
Mehssa Fritz  
James G. Gurney  
Division of Epidemiology/Clinical Research  
Department of Pediatrics / U of MN

**Presented by**  
Phill Sievers  
Consultant for Autism Spectrum Disorders  
Division of Special Education/DCIH.

## AUTISM SPECTRUM DISORDERS (Pervasive Developmental Disorders)



Number of ASD Cases in Minnesota  
from 1981 through 2000



## Autism Spectrum Disorders

MN Dept. of Children, Families & Learning

A range of pervasive developmental disorders that adversely affect a pupil's functioning and results in the need for special education instruction and related services.

A disability category characterized by an uneven developmental profile and a pattern of qualitative impairments in several areas of development:

- Social interaction
- Communication
- Restricted repetitive and stereotyped patterns of behavior, interests, activities

Autism Spectrum Disorder  
Incidence versus Prevalence

**Incidence:** the number (rate) of individuals with a newly diagnosed condition in a defined population, within a defined time period

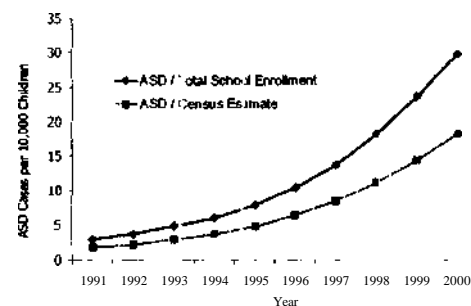
**Prevalence:** the number (rate) of individuals with an existing or newly diagnosed condition in a defined population, within a defined time period

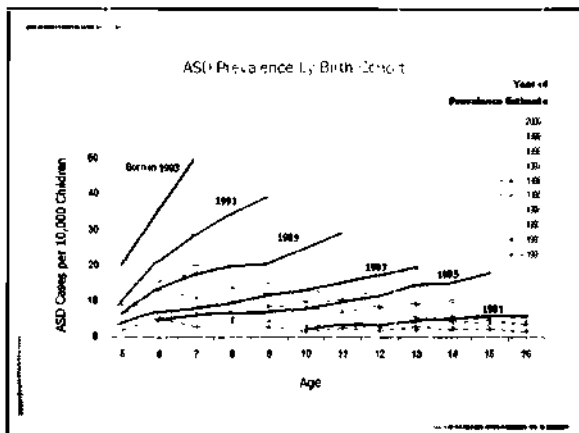
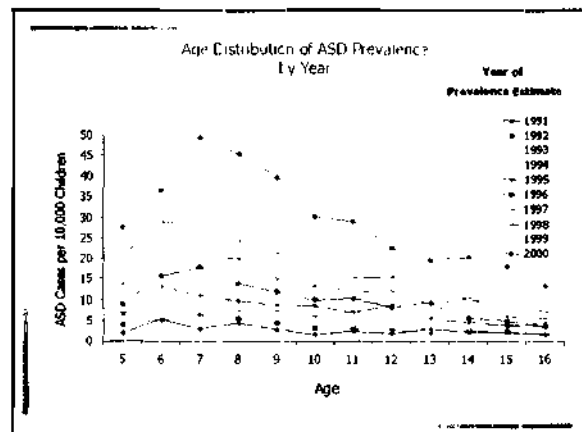
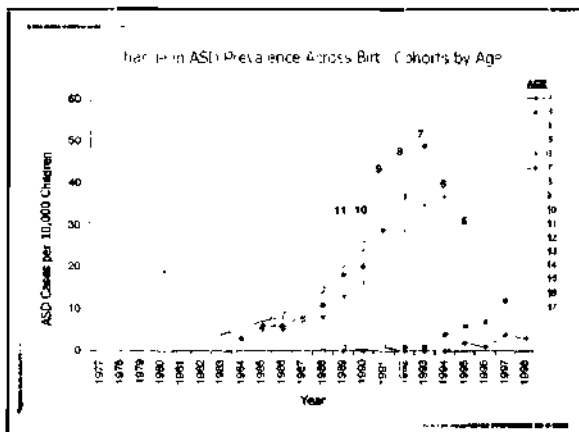
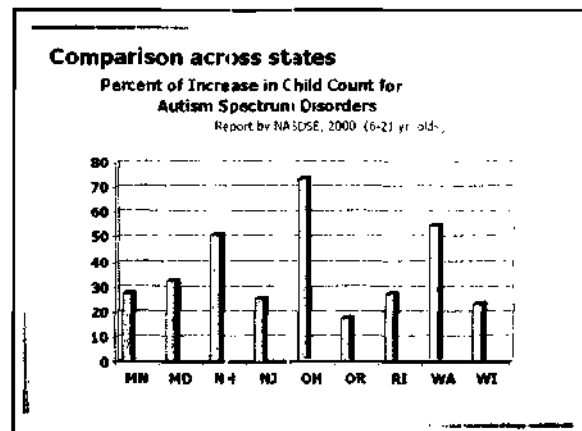
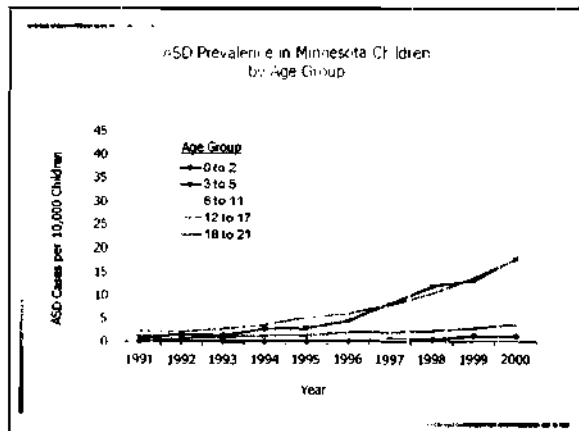
*Prevalence, is a function of incidence rate, duration of disease, and population migration.*

Because no population-based reporting mechanism exists for newly diagnosed ASD, it is difficult to estimate incidence and incidence trends

Our discussion today will focus on prevalence.

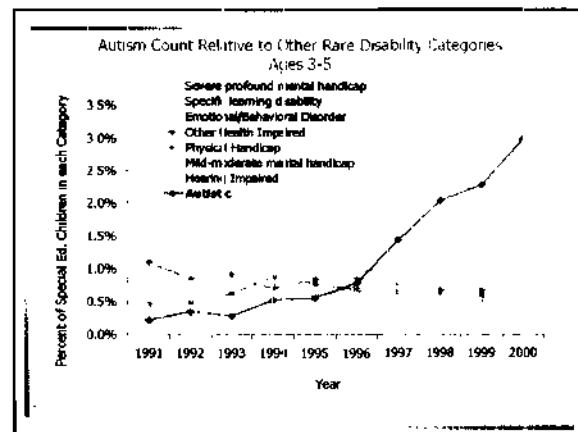
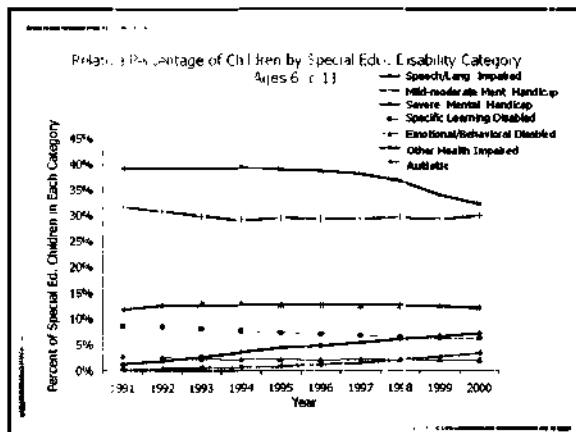
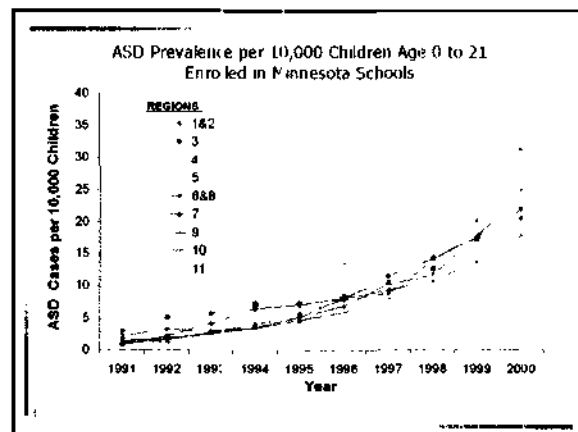
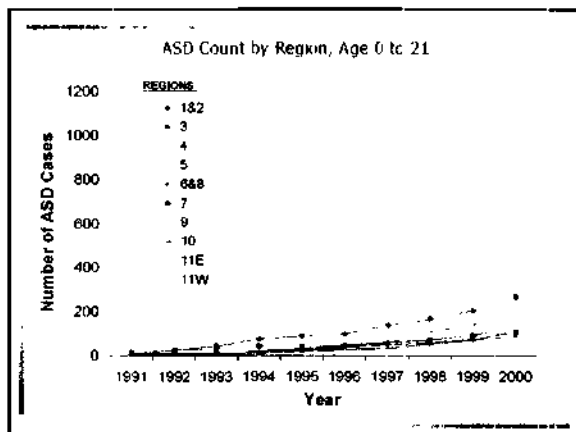
Prevalence of ASD among Minnesota Children  
1991 through 2000, Ages 0 to 21





### ASD Prevalence by Birth Cohort

Age	1989 Birth Cohort		1991 Birth Cohort		1993 Birth Cohort	
	Year	Prevalence Per 10,000	Year	Prevalence Per 10,000	Year	Prevalence Per 10,000
5	1994	11	1996	18	1998	21
6	1995	15	1997	21	1999	35
7	1996	18	1998	28	2000	49
8	1997	20	1999	35		
9	1998	20				
10	1999	25				
11	2000	30				



Estimated Future ASD Prevalence and Counts in Minnesota

Year	Based on Annual Increase of 32%	Based on Annual Increase of 25%	Based on 2000 Prevalence in 7 yr olds
2000	18 / 10,000 N = 2,814	18 / 10,000 N = 2,814	18 / 10,000 N = 2,814
2005	71 / 10,000 N = 10,827	56 / 10,000 N = 8,588	49 / 10,000 N = 7,409
2010	174 / 10,000 N = 41,660	171 / 10,000 N = 26,207	49 / 10,000 N = 7,345

Administrative changes that may have impacted trends?

- **1976** Education of the Handicapped Act (EHA) and the Elementary and Secondary Education Act (ESEA), U.S. Department of Education.  
9 EHA categories, ASD not a category  
6 ESEA categories, ASD not a category
- **1978** Multi-handicapped and deaf/blind categories added, categories under both laws made consistent
- **1990** EHA reauthorized, changing name to Individuals with Disabilities Education Act (IDEA) and revising several disability category labels

#### Administrative changes that may have impacted trends'

1991 Autism added to IDEA as a reporting category.  
All states now required to report the number of children receiving services for autism annually.  
Coincides with the beginning of the increase in autism prevalence rates

1992 MN Rule establishes requirement that an autism specialist be on the IEP team of any child suspected of having, or identified with an ASD

1992 CFL grant established the Minnesota Autism Network  
A statewide technical assistance and promising practices training project  
The goal of this project was to build capacity of staff districts and regions to provide appropriate services for individuals with ASD

#### Administrative changes that may have impacted trends?

- 1994 Funding for children with disabilities consolidated under IDEA.

IDEA now sole source of funding for ASD services  
Coincides with 1994 prevalence rate increase.

1997 CFL 3 year grant establishes ECSE/Autism Demonstration Projects

Coal of Projects: "to build capacity of staff, districts and regions to provide services specifically for young children with Autism Spectrum Disorders "

Focused on demonstration and dissemination of information intensive early intervention.  
Coincides with 1997 prevalence rate increase

#### Closing Thoughts

Prevalence rates are rising dramatically, and current prevalence may well be underestimated due to:  
the one child one diagnosis school policy  
the option of other disability categories (DD, S/L, MR.-)

Child Courts for ASD have risen substantially since 1990 and they show no current sign of leveling off

#### Projections

Even if the peak in identifying children with ASD has been realized, the school system will not reach an equilibrium for many years due to the cohort effect

#### Closing Thoughts., continued

#### Further Projection!..

If ASD prevalence stabilizes at the current rate of the 7 year olds (49 per 10,000), there will be 7000 children (birth to 21 yrs) included in the ASD disability category by this year 2005.

If prevalence continues to rise at the current average increase of 31% per year, Minnesota could see over 10,000 children in the ASD disability category in 2005.

Compared to the current ASD Child Count of 2814, any of these possibilities suggests that Minnesota will experience a significant increase in the challenges to families, schools and communities to provide appropriate education and support in the coming years



**Dec. 10, 2001**

**Response to the Request for Data from the Division of Special Education/DCFL on Autism Spectrum Disorders (ASP)...**

**Prepared by the Division of Special Education/DCFL**

The responsibility and cost for educating, raising and caring for children with ASD in Minnesota is typically shared between families, schools, other public agencies and community partners. The costs for Special Education and related services reflect only a portion of the actual costs incurred raising children with Autism Spectrum Disorders (ASD). In addition to Special Education there are numerous personal expenses funded by families for specialized health care, therapies and skilled child care providers as well as supports and funding provided through counties and the MN. Dept. of Human Services.

**The Request..."To the extent the data permit, your help with any of the following questions would be much appreciated."**

**1. "How many special education dollars are spent for autism-related services? "**

Students in Minnesota, from birth to 21 years, who are identified and receive services under the disability category of Autism Spectrum Disorders (ASD) are entitled to a free and appropriate public education (FAPE) in the least restrictive environment. The combined expenditures, including Extended School Year services, reported by school districts to DCFL for each of the past five years is summarized below.

<b><u>Years</u></b>	<b><u>Expenditures for Services* in ASD</u></b>
	(Includes all State and Federal Special Education Aids)
1996	\$5,335,682
1997	\$6,041,292
1998	\$7,877,446
1999	\$10,877,589
2000	\$13,647,649

\* Source for data is the DCFL Division of Special Education - Electronic Data Reporting System (EDRS). The report for Service Crosstabulation by Disability -Autistic includes: Service expenditures reported by all local school districts, Low Incidence Regional Autism Projects, and expenditures for Part C (Birth-3 yrs.) and 619 (Preschool) including Extended School Year (ESY) services

**2. "What is the nature of these services?"**

Services provided and coded for in these expenditures include teaching and paraprofessional personnel, expert consultation, instructional supplies and equipment, staff travel, personnel development, etc. A complete listing and description of all services and their codes is available in the

DSE manual "Funding Special Education: A Handbook for Administrators" pages 33-45 and can be accessed electronically by linking to [http://cfl.state.mn.us/SPECED/Giidelines/budaet\\_manual.pdf](http://cfl.state.mn.us/SPECED/Giidelines/budaet_manual.pdf)

### 3. "How many children are served as a result of these expenditures?"

The following data summarizes the number of individuals, birth to 21 years, receiving Special Education and related services in Minnesota, who have been identified and reported with a "primary disability" of ASD.

<u>Year</u>	<u>Dec. 1 Child Count *</u>
1996	975
1997	1,283
1998	1,732
1999	2,242
2000	2,814

The dramatic increase observed in the number of individuals identified in this category is consistent with national and international reports. Individuals counted in this eligibility category demonstrate a spectrum of disability conditions that include Autistic Disorder, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), Atypical Autism, Asperger's Disorder.

The 3 common core features of this ASD category are:

1. Qualitative impairments in social interaction and
2. Qualitative impairments in communication and /or
3. Restricted, repetitive, or stereotyped patterns of behavior, interest, and activities

The trend over the past 5 years indicates a 189% increase in students eligible under the ASD category in Minnesota. Child Counts for ASD have risen substantially since 1990 and they show no current sign of leveling off. It is believed that this increase is due in part to several factors including; 1) better public awareness, 2) improved identification methods and staff training, 3) research supporting a broader understanding of the category as a spectrum of disorders and 4) the possibility of a true increase in the prevalence.

An "Autism Spectrum Disorders: Descriptive Study" was recently completed in collaboration with the U of MN and suggests that these data are still conservative counts because they are based on an unduplicated count and the possibility that these students may be eligible and therefore counted in another category such as Developmentally Delayed. Using the Dec. 1,2000 Minnesota Child Count that reported 2,814 individuals with ASD (birth-21 yrs.) and current prevalence rates, the projected Child Count for ASD in the year 2005 will likely be between 7,000 -10,000 individuals.

It may be that the communities' awareness level will reach its peak in the next few years but the data trends show no current sign of leveling off. Even if the peak in identifying children with ASD has been realized, the school system will not reach an equilibrium in the Child Count for many years due to the age cohort effect identified in the study.

The 'Autism Spectrum Disorders: Descriptive Study' (Power Pt. Presentation) and "Executive Summary" of 10 year trends, by regions and age groups in Minnesota and future projections is attached.

\* Source of data is the DCFL Division of Special Education - Unduplicated Child Count for students birth to 21 years of age, identified and served under the categorical label of Autism Spectrum Disorder (ASD).

#### 4. "What is the average cost per child?"

Since this group of students represent a wide spectrum of ability/disability and educational needs, the individually planned and provided Special Education and related services, are typically quite varied. Individual students in this category most often demonstrate more severe disabilities and need for intensive services while other students may require less service. The average expenditure per child is indicated below.

<u>Year</u>	<u>Total *</u>	<u>/</u>	<u>Child count</u>	<u>=</u>	<u>Average annual Cost per child</u>
1996	\$5,835,682		975		\$5,985
1997	\$6,041,292		1,283		\$4,708
1998	\$7,877,446		1,732		\$4,548
1999	\$10,877,589		2,242		\$4,851
2000	\$13,647,649		2,814		\$4,849

\* Total annual expenditures for Special Education and Related Service including ESY services..

#### 5. "To what extent is MA billed for the autism-related services provided in schools? "

School districts can bill Medical Assistance (MA) for some IEP services provided for individuals with Autism Spectrum Disorders, if parents give them permission to access MA \$. In general the number of districts billing MA, for IEP Services has increased from 17 districts in Jan. 2001 to 88 of 402 districts submitting bills for IEP services in Nov. 2001. Billing requests from districts to MA are made in pre approved procedure categories and do not require them to identify a child's medical diagnosis/condition on their bill. Therefore, these MA payments made to districts cannot be sorted by such categories as autism spectrum disorder and the extent that MA is billed for autism-related services cannot be determined at the state level. (Genie Potosky- DHS [Genie.Potosky@state.mn.us](mailto:Genie.Potosky@state.mn.us))

#### 6. "To what extent are private insurers billed for such services?"

Districts report the total amount billed to private insurance for all Special Education services appropriate for such funding. This data is not reported to DCFL or broken down by specific disability categories. Therefore, it is not possible to determine the extent that private insurers are billed by districts for autism-related services except at the local district level. (Tom Delaney- DCFL, Tom [Delaney@state.mn.us](mailto:Delaney@state.mn.us))

**7. "Are other DCFL pass-through dollars, beside special education dollars, spent for autism-related services? "**

Some additional dollars are directed specifically to projects that support capacity building activities across the state. These include the following...

Low Incidence Federal Discretionary funds to provide Technical Assistance and Outreach via Minnesota State Autism Network activities in 1999-2000 =	\$ 152,000
Parent and Family Grants =	<u>\$17,800</u>
TOTAL =	\$169,800

Dec. 6, 2001

**Response to the Request for Data from the Division of Special Education/DCFL on Autism Spectrum Disorders (ASP)...**

**Prepared by the Division of Special Education/DCFL**

The responsibility and cost for educating, raising and caring for children with ASD in Minnesota is typically shared between families, schools, other public agencies and community partners. The costs for Special Education and related services reflect only a portion of the actual costs incurred raising children with Autism Spectrum Disorders (ASD). In addition to Special Education there are numerous personal expenses funded by families for specialized health care, therapies and skilled child care providers as well as supports and funding provided through counties and the MN. Dept. of Human Services.

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The trend over the past 5 years indicates a 189% increase in students eligible under the ASD category in Minnesota. This general trend is consistent with the dramatic increases reported nationally and internationally for the past 10 years. An ASD Descriptive Study was completed in collaboration with the U of MN and suggests that these are still conservative counts because they are based on an unduplicated count. Based upon the Dec. 1, 2000 Minnesota Child Count that reported 2,814 individuals with ASD (birth-21 yrs.) and current prevalence rates, the projected Child Count for ASD in the year 2005 will likely be between 7,000 -10,000 individuals.

An Executive Summary and Power Pt. Presentation of 10 year trends, by regions and age groups in Minnesota and future projections is attached.

Source of data is the DCFL Division of Special Education - Unduplicated Child Count for students birth to 21 years of age, identified and served under the categorical label of Autism Spectrum Disorder (ASD).

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Parent and Family Grants = \$17,800

TOTAL = \$169,800